

# **The National Council for Priority Setting: A transparent decision- making?**

Silje Øygard Melsether



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Department of Health Management and Health Economics  
The Faculty of Medicine

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Silje Øygard Melsether

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# Abstract

*Objective:* The objective of this thesis was to find out if the Norwegian Council for Priority Setting in Health Care (the Council) has succeeded in its attempt towards transparent decision-making.

*Background:* Accountability for reasonableness (A4R) is a framework used to strengthen decision makers accountability and legitimacy. This framework uses four criteria to ensure fair decisions. One of them is publicity. Publicity and transparency is closely linked together. When the Council was appointed in 2007, one of their most important tasks was to ensure a transparent decision process.

*Method:* In this thesis a framework for transparency is developed and used to evaluate the transparency of five case documents that are published online, and the availability of the cases on the Council's website, [www.kvalitetogprioritering.no](http://www.kvalitetogprioritering.no).

*Results:* Several shortcomings were identified. Decisions were not fully justified. The case process was standardised, but what evidence and how they were collected was not. The ability to track decisions over time was not possible in all cases. Additionally, abbreviations, expressions and conditions that were important for decision making were not detailed nor explained. All cases evaluated used a technical language and long sentences. The cases of more recent date were more reader friendly. The availability of the cases published online could be better. What is published of important information needs attention and the website needs an upgrade.

*Conclusion:* The Council is a pioneer in setting priorities in health care. By making documents and minutes of meetings publicly available online, the intention is to increase document transparency. However, placing documents on a website is not synonymous with making the documents transparent. The evaluation shows that the level of transparency can improve.

**Disclaimer:** The findings, interpretations and conclusions expressed in the paper are entirely those of the author, and do not represent the views of the National Council for Priority Setting in Health Care.

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List of Abbreviations:

A4R	Accountability for reasonableness	
CI	Cochlea Implant	
EPDS	Edinburgh Postnatal Depression Scale	
FHI	Norwegian Institute for Public Health	Folkehelseinstituttet
FOBT	Faecal Occult Blood Test	
HDIR	The Norwegian Directorate of Health	Helsedirektoratet
HELFO	Norwegian Health Economic Administration	
HF	Health trust	Helseforetak
HOD	The Ministry for Health and Care Services	Helse og omsorgs- departementet
MA	Monoclonal Antibodies	
NC	National Council for Priority Setting in Health Care	Nasjonalt råd for kvalitet og prioritering i helse- og omsorgssektoren
NHCP	National Health Care Plan	Nasjonal helse og omsorgs plan
NNO	Norwegian Nurses Institute	Norsk sykepleierforbund
NOKC	The Norwegian Knowledge Centre for Health Services	Kunnskapssenteret for helse
PD	Postpartum Depression	
POBO	Health and Social Services	Ombudsmann
QUALY	Quality Adjusted Life Years	Kvalitetsjusterte leveår
RHA	Regional Health Authorities	Regional Helseforvaltning
SAK	Norwegian Registration For Health Personnel	
TAVI	Trans catheter aortic valve implantation	

VA	Vaccination against rotavirus	
WHO	World Health Organization	Verdens Helse Organisasjon

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# 1. Introduction

As a part of a governmental strategy towards accountable and legitimate decisions in health care, the Norwegian Council for Priority Setting (the Council) opened in 2007 (HOD 2007-2010). According to the National Health Care Plan (NHCP) 2007-2010, its main task was to create accountability and legitimacy for decisions made by politicians. One of the main strategies the Council used to achieve this was transparency. The idea is that if one understands why one is being denied health care services, it will be easier to accept a refusal (Nordheim 2005).

In this thesis a framework for transparency was developed. The framework was used to evaluate the Council's website and five priority setting cases.

## 1.1 Research question

The research question examined in this thesis is:

*Have the Norwegian Council for Priority Setting in Health Care succeeded in its attempt towards transparent decision-making?*

## 1.2 Thesis structure

Chapter 1 is the introduction to the thesis. Chapter 2 explains the background for the study and its importance. Chapter 3 introduces and elaborates the existing practice when it comes to priority setting in Norway. The National Council for Priority is presented in this chapter. Chapter 4 gives a theoretical background presenting a framework for fair decisions. A deliberative decision process is explained, and the concept of publicity and transparency is defined. Chapter 5. The framework for transparency is presented for the first time in this chapter. Chapter 6 outlines the study design, the search strategy used to identify relevant transparency criteria and data material. In chapter 7 five cases that limit access to different kind of health care is described. Chapter 8 contains the evaluation and its findings. Chapter 9 discuss not only the findings of the evaluation, but strengths and weaknesses with theory, method and the framework for transparency. Chapter 10 concludes this study and gives reflexions of the Councils potential.

## 2. Background

Healthcare priority decisions are fundamentally ethical decisions. By prioritising one treatment there are always treatments- *and patients*- that are not prioritized.

The existing technology and the expectations of the services are greater than, not only what the public health can, but also what it is willing to offer (Norheim 2005). This can be illustrated by the “health gap” which shows the need for priority setting decisions.

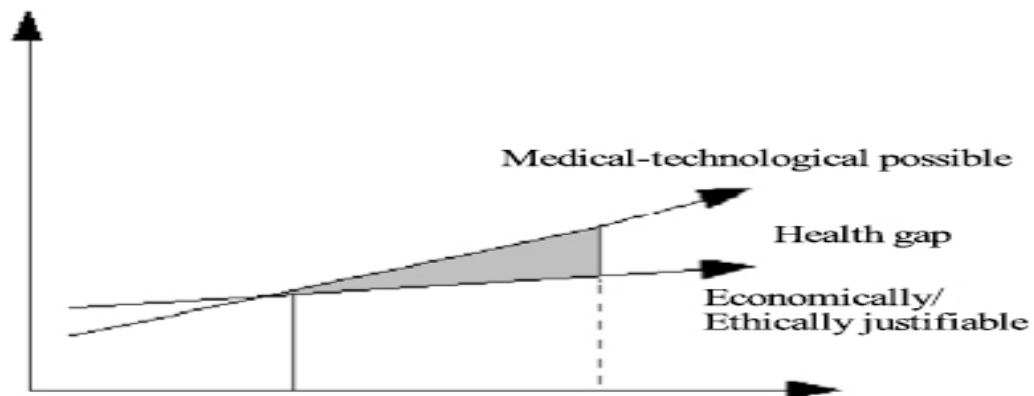


Figure 1: The Health Gap (HOD 1997)

As a result of a distrust in how governmental resources and money was spent, the process of prioritization — how one actually came to the decision, became important in the late 90`s (Feiring 2005).

When the Council was opened in 2007, the Council decided to have an open and transparent decision-making process. Ringard, Mørland and Røttingen describe how the Council came to the conclusion of a transparent decision – making process in their article “Åpne prosesser for prioritering”. The main argument was to avoid discussions about what had been said and done at council meetings (Ringard et al. 2010). In the end of this article, there is an invitation to evaluate if the ambition of an open/transparent process has been reached. This thesis is an answer to the mentioned invitation.

Sabin and Daniels developed a decision-making procedure that assists in creating consensus in what would be a legitimate and a fair way to make a decision. This thesis reviews and evaluates the transparency of five limit setting decisions in the light of one of four criteria in Daniels and Sabin´s framework “Accountability for reasonableness” (A4R), namely the



publicity criteria. Being publicly, in the sense that it is also readable and available, also means being transparent. Transparency about the basis and justification for decisions is one of the key elements (Sabin and Daniels 2002).

There have been several studies of the process of decision-making using all four conditions (publicity/transparency, relevance, revision and appeals and regulation) of A4R worldwide. The results concerning whether documents regarding priority setting in health care are transparent in the light of Daniels and Sabin's framework A4R are divergent amongst different researchers. Most studies show that priority-setting decisions have some degree of transparency. The conclusion in the evaluation of six cases from the Swedish Pharmaceutical Benefits Board (LFN) was that the cases were transparent (Jansson, 2007). Even so, and despite the fact that transparency is highly valued in the process of decision-making, most research show significant gaps in the publicity condition (Schlander 2008, Syrett, 2011). A formal mechanism of making priority - setting decisions known, is lacking (Bukachi et al., Omar et al., 2013). Even in cases with high level of deliberation, the rationales for decisions were missing (Daniels, 1999).

The degree of transparency has an effect on how one value decisions that have been made in terms of limited access to health care. However studies that evaluate transparency in the light of A4R, indicate that the framework is inadequate (Friedman, 2008). In Kapiriri et al's article *"Fairness and accountability for reasonableness. Do the views of priority setting decision makers differ across health systems and levels of decision making?"* it is said that even though A4R have been used to evaluate and improve fairness of priority setting, it has also been criticised for not providing the exact content of the process. This may explain why we find different practices on making the rationales behind the decisions open to the public.

The value of developing a framework for transparency becomes clear in this context. A transparent decision gives insight into how the government actually allocate resources and on what basis. With a framework it is easier to know what transparency is, and how to ensure transparency in decision-making. A framework will also make it is possible to compare different organizations and say something about the different levels of transparency.

## 3. Priority setting in the Norwegian Health Care Services.

It is important that setting priorities are appropriate and consistent with health policies, rules and norms that apply to Norwegian health service. This chapter describes the background for and existing practise when it comes to priority. The history of, and the organisational context of the Council is also presented in this chapter.

### 3.1 Priority setting in practise

Priority setting is performed at two different levels in Norway. At an overall level, the central government and management controls the economic, legal and organisational framework. Prioritising between different types of schemes for prevention, treatment and emergency care happens here (HDIR 2012). Through guides and guidelines for best practice, the Norwegian directorate of health (HDIR) (and other professional bodies) is responsible for supporting the right priorities. Through the allocation of resources, the size of different health services is determined. Budget decisions in Parliament, gives Regional Health Authorities (RHA), Hospital Trusts (HF) and local authorities a financial framework.

At the subordinate level prioritisation occurs both in primary health care and at specialist health care in hospitals. The principal priority – setting at this level happens in the encounter between patient and healthcare provider. General Practitioners (GP) act as a gatekeeper to the specialist healthcare. Whether Patients have a right to specialist healthcare is based on the GP's professional opinion and discretion. Professional standards in the selection of patients for proper diagnosis, assessment or treatment are defined. In the specialist health services, guidelines for priority – setting is developed - and intended to support decisions about individual patients and their rights (HDIR 2012).

### 3.2 Priority commissions:

Lønning I and Lønning II, are two commissions that have thoroughly discussed what kind of health needs should be prioritized. Their focus was the different processes behind prioritizing practise. Different conditions that should form the basis for priorities and guidelines, for both

patient groups *and* individual patients, were developed. They focused on five dimensions of healthcare.

*Table 1. Five dimensions for priority*

Five dimensions for priority	
1	Severity of disease
2	Equal opportunities for treatment
3	Health economic aspects
4	Waiting time
5	Patients responsibility for disease

(HDIR 2012)

In 1987 Lønning I submitted the Norwegian White Paper ”Retningslinjer for prioriteringer innen norsk helsevesen”. This paper concluded that severity should weigh heaviest in priority decision, at both priority levels. However, the severity condition gave too much room for interpretation and discretion. Ten years later, Lønning II, came with a new report “prioritering på ny”. Lønning II found, based on the work of Lønning I, that there were three conditions that should be especially important in priority setting. Severity of disease, effect of treatment and cost-effectiveness. For a treatment or service to be prioritised, all three conditions must be present (HDIR 2012).

Table 2. Three conditions for priority

	Three conditions for priority	
1	Severity of disease	Without treatment, the quality of life, or length of life will be significantly reduced
2	Effect of treatment	Requires good scientific evidence that a condition can be improved by medical treatment
3	Cost-effectiveness	There shall be a responsible relationship between cost of treatment and expected effect of treatment

(HDIR 2012)

A new priority commission was appointed in June 2013 HOD. The commission shall go through principles, criteria, methods and processes for prioritization. How the current official prioritization conditions can be operationalized and weighted will be looked at, in addition to new prioritization criteria such as age and rarity. The Commission will present its work by 15. September 2014 (Nasjonalt Råd 2013 F).

## 3.3 The Council

### 3.3.1 History

The first time a council for priority was mentioned was in the report from Lønning I in 1987. Three years later the “Bondevik government” appointed a council for priority. This was a continuation of the former state hospital council (Sundar 2002). In 2002 when HDIR was established, HDIR got the responsibility to assign a secretary for the Council. There is little information about the Council and its activities the first years. In 2006, for unknown reasons, the Council was closed down. However, in 2007 it was reopened as part of a general strategy for quality, patient safety and prioritization (HOD 2007-2010). The Council was ment to be a meeting point for people in positions with responsibilities regarding quality and priority decisons in the healthcare sector. The thought was that if resources are prioritized and

allocated properly, it leads to a health service with good quality (Janbu 2007). The Council is now in its second mandate (authorization to act in a particular way, normally four years at a time). During the Council's first period (mandate) there was a tendency that only cases associated with specialist services were discussed. To make it clear that the Council was a council for health care services as a whole, and not just the specialist health care, its mandate was expanded and the Council renamed. The name changed from National Council for Quality and Priority Setting in health care to National Council for Quality and Prioritizing in health care – *and care services*<sup>1</sup>. Both the Council's new name and the new mandate emphasize public health and prevention to a greater extent. In addition, the right to propose cases was expanded. Earlier it was only the Council members and the secretary that could propose cases, now everyone that wants to, may submit proposals through a form on the website.

---

1

National Council for priority is the official english name as stated on [www.prioritysetting.no](http://www.prioritysetting.no). Nasjonalt råd for kvalitet og prioritering i helse- og omsorgstjenesten is the official Norwegian name.

Table 3. Mandate for current period

	<b>The Council's mandate for current period</b>
1	Principles for priority setting, including both the municipal (local) and specialist health services.
2	Questions as to whether any unacceptable discrepancies are developing in the provision of services across professional fields, geographical areas or social groups, and advice on how to counteract such differences.
3	Questions related to the introduction of new and costly technology/treatment options in the health and care sector.
4	Questions related to the distribution and use of national services in the specialist and primary health care service.
5	Questions related to the development of national official guidelines in special medical fields in order to ensure an equal and fair distribution of the services provided by the health sector, of high professional quality.
6	Questions related to collaboration between the specialist health services and municipalities, including preventive work, public health, care services and treatment options that affect quality, distribution of tasks and thus the setting of priorities and the distribution of resources and skills among the different levels involved in the Norwegian health service.
7	The council is to be involved in the assessment of medical measures involving the public, including screening and vaccination programmes.
8	The council is to advise on priorities with regard to publicly initiated clinical research trials.

(Nasjonalt råd 2013 J)

### 3.3.2 Organization

The Council is a part of the Norwegian Health Management (helseforvaltningen), which has a hierarchical structure. The health care system in Norway is a complex, heavily regulated system. In Norway, health care services are (mostly) paid by federal government. On top, we have the Ministry of Health and Care Services (helse og omsorgs departementet) (HOD). HOD has the overall responsibility for the health service system. In addition to its responsibility for politics, public health, health services, municipal services to elderly and

disabled, and laws and legislation it also has responsibility for parts of the social security benefits program financed by taxes in Norway (HOD 2013).

The Norwegian Directorate of Health (HDIR) is an important subordinate agency to HOD. HDIR gives advice about public health, living condition and health services. HDIR gives guidance about strategies and measures aimed at central government (and others). HDIR is responsible for ensuring that their policies and advice is according to the guidelines they get from HOD in the annual letter of allocation (tildelingsbrev) (HDIR 2014).

The Norwegian Knowledge Centre for Health services (NOKC) is organized under HDIR. NOKC supports the development of programs and initiatives to improve quality of health care services. By Summarizing research NOKC is contributing to the use of research results, in addition to measuring the quality of health (NOKC 2013).

The secretary function of the Council is located at the NOKC and is like NOKC both professionally and scientifically independent.

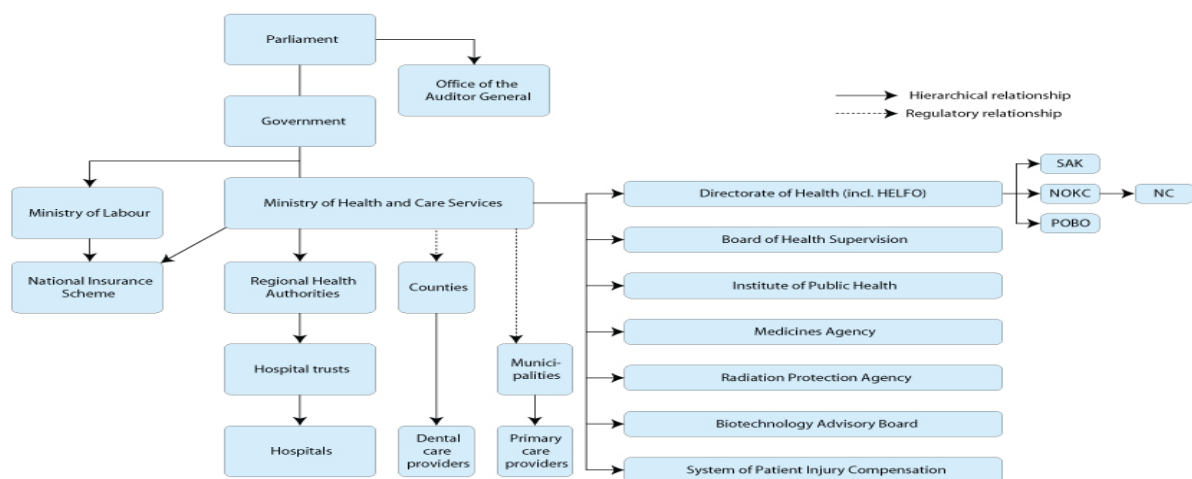


Figure 2. Overview of the health system (adjusted from Ringard. et.a el. 2013)

*NOKC = Norwegian Knowledge Centre for the Health Services; POBO = Health and Social Services Ombudsman; SAK = Norwegian Registration Authority for Health Personnel; HELFO = Norwegian Health Economic Administration NC=The Norwegian Council for Priority setting in health care.*

Organizationally the Council is divided into two parts. One part consists of five full-time workers and represents the Council's secretariat. The objective of a transparent decision lies within the secretary. The approaches used to accomplish transparency are: 1) open meetings, 2) online documents, 3) newsletter, and 4) a conference. Case preparation is the most important work the secretary does. Last, but not least the secretary is responsible for the website, both the Norwegian and the English version ([www.kvalitetogprioritering.no](http://www.kvalitetogprioritering.no) and [www.prioritysetting.no](http://www.prioritysetting.no)) (Nasjonalt råd 2014 H).

The other part consists of 26 executive members appointed by HOD (Ringard et al. 2012). They constitute the elite body of the Council. The Council members is chaired by the head of HDIR, and consists otherwise of persons in responsible positions in the regional health authorities, local authorities, patient organizations, universities, colleges and trade unions. This means that agents with responsibilities in health care have meetings where they discuss key issues. Decisions they make may have an impact on priority at the overall level (ref.ch 3.1). Their task is to make assessments and give recommendations in quality and priority issues through a deliberative discussion (Nasjonalt råd 2013 G).

The Council's composition makes it appear heavy and influential. This ensures a good grounding in the executive service and the implementation force is strong (Janbu 2007). However, it is not in the hands of the Council to decide what should be prioritized or not, but to provide a well worked through review of the individual case at hand, and give recommendations to the ruling government. HDIR has a special responsibility to make sure that the recommendations are followed up. The Council members also have an individual responsibility. This is to take those initiatives where they think is necessary, making sure that the issues recommended are implemented and followed up (Janbu 2007). Annually the Council has five meetings where Council members discuss different cases. The cases are divided in to three groups. Cases for debate, cases for information and case themes.



## 4. Theoretical Framework

One of the most important forms of governmental administration is the publicity of public documents. There are two laws that specifically regulate public access to documents. These laws are briefly described in this chapter. The framework “Accountability for reasonableness” (A4R) is looked at and elaborated. A closer look at the publicity condition is essential, and the inherent link between publicity and transparency will be explained. The concept of deliberation is also presented.

### 4.1 Access to public decisions

The right to access government records is regulated in Act of 19 May 2006 No. 16 (Short title: the Freedom of Information Act) and Act of 10 February 1967 relating to procedure in cases concerning the public administration as subsequently amended, most recently by Act of 1 August 2003 No. 86 (short title: Public Administration Act). The Public Administration Act is a general law, used in all procedures, as long as no other law applies for special legislation. This act regulates individual rights when in contact with regulatory agencies. It safeguards the individual's rights and shall ensure adequate procedures. This means that within government it regulates impartiality, duty to provide guidance, time spend dealing with a case, confidentiality and complaints on decisions.

The freedom of Information Act on the other hand, allows access by the public to data held by national governments. The purpose is to make sure that public companies are open and transparent, strengthen information and freedom of expression, democratic participation, the rule of law for individuals, the trust of the public and control from the general public (Lovdata 2006). In general, the Freedom of Information Act, says that all documents shall be open and accessible. The Council is under regulation of both the Freedom of Information Act, and the Public Administration Act. It is important to know that certain regulation and procedures followed in order to ensure the quality of the decision process. The law that regulates accessibility is considered as an important part of citizens' rights to access public documents.

## 4.2 Accountability for Reasonableness

“Being accountable means that you take responsibility for your actions, while reasonableness means that something is perceived as fair”.

A4R is a theoretical framework for a deliberative consideration of documentation and values. The core idea is that decision makers must justify their decisions in a reasonable and relevant way when it comes to priority-setting decisions in health care. With a fair process of setting limits, decision makers become more accountable for the decisions they make (Daniels 2008). If decisions are based on qualified and evidence-based research, decision makers are able to defend their actions and answer to critical questions. This helps make it apparent that the decision makers indeed are accountable for their decisions. However, the main reason for A4R was not to make decision makers accountable for their choices, but to enable people to understand why, and under what conditions decisions that affect them are made.

Daniels and Sabin argue for four conditions that must be present for a decision to be reasonable. The four conditions are the relevance condition, the publicity condition, the revision and appeals condition, and the regulative condition.

*Table 4. A4R's four condition.*

A4R`s four conditions	
Relevance	Rationales for priority setting decisions must rest on reasons that stakeholders can agree are relevant to the context. Arguments should rest on scientific evidence.
Publicity	Decisions regarding both direct and indirect limits to care and their rationales must be publicly accessible.
Revisions/appeals	There must be an institutional mechanism to engage society in the process, and a possibility to reopen the deliberative process in light of further argument.
Regulative	Leaders in the priority-setting context are responsible that the three other conditions are met.

### **4.3 A deliberative process**

To ensure that a decision is being more legitimate and decision-makers more accountable, a deliberative context is a requirement in A4R. In theory, a deliberative process is both concerned with justice (Rawls tradition) (White 2011), and communication techniques (Habermas tradition) (Peierce et al. 2008). In practise, by allowing participants to listen, understand and potentially persuade the other participants hopefully a more informed decision can be taken. By providing a deliberative participation in morally complex and challenging decisions in health care, one makes sure that the discussion highlights more aspects in a case. Citizens may contribute with information, and ask critical questions.

In a deliberative process, the way you arrive at a decision is more important than the decision alone. Deliberation test subjective opinions, builds knowledge based on evidence and makes decisions accessible, accountable and transparent (Gauvin 2011). Traditionally deliberation has been associated with elite thinking. Societies most trusted men and women have the responsibility so that decisions made on behalf of the population are thoughtful and reasonable. There are both normative and practical reasons as to why elite deliberation is preferable. The normative justification is that not everyone should participate in a discussion. It runs partly on the basis that those who have the most education and who has proven skilled within an area, also have the best judgment in political matters. The practical reason is that not everyone can participate in a discussion. In practical terms, it is impossible do to let an entire population say it's meaning every time you have to make a choice (Offerdal, Aars).

### **4.4 Publicity and Transparency**

Publicity and transparency are two different concepts, but meaningful publicity requires transparency. The term transparency can be defined as an understandable, open and accessible process, with information about the reasons and background for a decision. The concept of transparency captures the availability of information (Curtin and Meijer 2006). A transparent decision makes it possible for people outside, not only to access information, but also to understand the context and rationale behind the decisions in order to form opinions about actions and processes within (Neurin et. al. 2007). Publicity on the other hand means that the information is actually spread to, and taken in by the public. Publicity is when the media gives attention to something or someone. Information or news is provided in order to gain public or

media attention for a person, event or place (Oxford dictionary 2013). Put differently, transparency implies that there is documentation available on the background for a decision, while publicity means that the public also knows of the existence of this information. Transparency increases the chances of publicity (Neurin et. al. 2007).

In order for a decision to be conceived as fair, it is easy to see that transparency and public involvement, as required by the publicity condition in A4R, must be present. However since the condition do not have any refinements or criteria to how public documents are made public; this varies from case to case, and from organization to organization.

## 5. Framework for Transparency

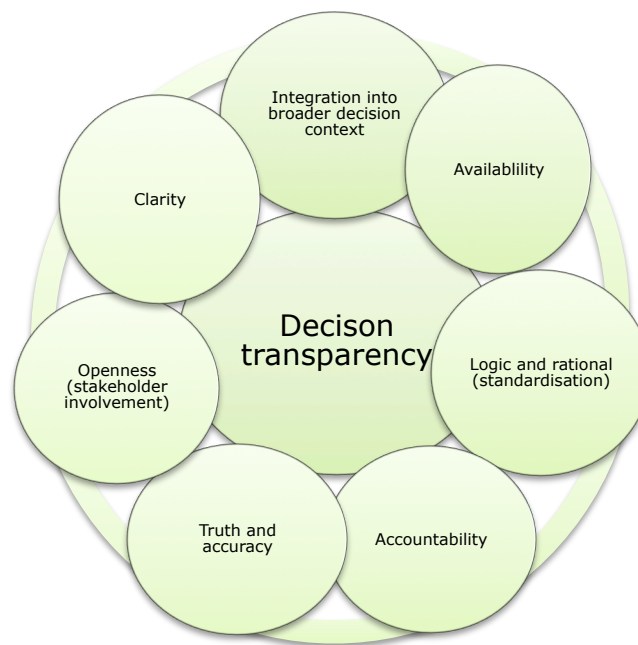
The use of a variety of theories makes a framework a practical and pragmatic tool. Without necessarily implying a unique answer to all issues, a framework assists in reaching a reflected insight, and makes it possible to extract relevant information (Kaiser Et.al.2006).

Organizations and individuals who make priorities in health care at the overall level are the targets for the transparency framework. The main goal is to ensure that political decisions in health care are available, and that interested parties have access to the rationale behind priority decisions. The ambition is to contribute to the understanding of what a transparent decision-making is. It is hoped that the framework can be an important practical tool when the target is transparent decision-making in health care.

A framework for understanding and evaluating transparency regarding nuclear waste clean up has heavily influenced the work of this thesis. Drew et. al. (2004) found that there were few good measurement techniques for transparency and wanted to address this gap. Even though nuclear waste and health care are far from each other in contents, the intention and aim towards accountable and legitimate decisions are the same.

In the paper "Transparency of environmental decision-making: a case study of soil clean up inside the Hanford 100 area" seven objectives for decision transparency emerged from a literature review (Drew and Nyerges 2010).

### SEVEN OBJECTIVES FOR TRANSPARENCY



*Figure 3. Seven Objectives of Transparency*

(Drew and Nyerges 2010).

All of the seven objectives are important, but only four have been selected as basis for decision transparency analysis (Drew and Nyerges 2010). By using the four objectives as inspiration, a framework for transparency was developed (table 5).

Table 5. Objectives, sub objectives and instrument in framework for transparency

Objective	Sub objectives	Instrument
Contextual integration	Complete Consolidated Referencing system Table of contents	Questions
Standardisation	Follows routines Follows processes that are consistent, standardized, formalized, flexible, expandable Identifies clear decision points and important values Allows users to track decisions and policies over time	Questions Conditions for priority
Clarity	Straightforward Understandable Unambiguous	Greentext
Availability	Access to important meetings Access to government documents Makes detailed documentation and databases available Two way access to information	Questions DIFI

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It is important to point out that the framework for Drew and Nyerges has only been used as a template. This means that it has been used many of the same components, and many of the same questions have been set, but there are also major differences.

## 5.1 Contextual integration

Integration is about placing the decision at hand in wider context (Drew and Nyerges 2004). Information, science and knowledge should lie behind every decision and advice given by the Council. By integrating a case it should be easy to find information and references. The case documents should contain the decision fully laid out, background information, different alternatives to the decision, in addition to a brief summary of the document. Citations in the text are required, as well as a complete reference list, list of abbreviation and table of contents.

Rating: M=fully met, P=partially met, N=not met.

*Table 6. Questions asked to evaluate degree of integration*

	Questions	M	P	N
1	Is the decision fully justified?			
2	Is background information provided?			
3	Are different alternatives to the decision available?			
4	Is a consolidated document provided?			
5	Are there citations in the text?			
6	Is there a reference list?			
7	Is there a list of abbreviation?			
8	Are there a table of contents?			

## 5.2 Standardisation

A logical and rational decision requests a consistent, standardised and formalised process. A standardised procedure ensures equal treatment of cases and a plan on how achieve the objective is required. Planning is a part of a rational decision-making. Each step in the decision process builds logically on each other (Kleven 2014).





Figure 4. Process plan

Clear decision points and the rationale behind the decision are crucial. Why a particular decision occurred and what values underlie the decision factors must come across (Drew and Nyerges 2004). Priority setting in health care is increasingly based on explicitly formulated values that are well known and acceptable (Defecheraux et al. 2012). The principle of equal treatment in health care is of ethical value, and an important goal in healthcare. The Lønning conditions are an attempt at putting the principle of equality in system.

The presence of severity, efficiency and cost effectiveness are therefore all considered important when it comes to priority decisions. The conditions have been subject for discussion and interpretation, but are still leading points in how to prioritise (HDIR 2012).

Table 7. Sub objectives for a Logic and Rational decision - making process

Sub objectives		M	P	N
1	Follows routines and a defensible plan			
2	Follows processes that are consistent, standardized, formalized, flexible, expandable			
3	Allows users to track decisions and policies over time			
4	Takes the priority conditions into consideration			

## 5.3 Clarity

Clarity means that something is understandable (Drew and Nyerges 2010). Clear language is not only about what you are writing, getting a clear understanding also depends on who you are writing for, i.e. the target audience. Patients, doctors and journalists are examples of people that may be interested in the rationale behind how priority decisions are established.

What information is required and what kind of information is excessive are important parameters when it comes to document clarity (Willumsen 2013). Unclear language can create distance between sender and receiver. Clear and concise language, helps the recipient to easily perceive the sender's message, and reduces the risk of misunderstandings (Språkrådet 2013). To illustrate clarity Drew and Nyerges (2010) ask questions like “*Is it well written? and Do we need technical knowledge to interpret?* “, and leave it to the individual's subjective experience to assess the linguistic quality.

### 5.3.1 Greentext

This thesis has used Greentext, a tool to analyse texts linguistic quality, has been used to evaluate linguistic quality. Greentext (2012) is designed for writers to see where the document needs amendments to make the document more reader friendly. Greentext is a web-based subscription service that focuses on texts verbal design. It is a working tool that replaces mere assumptions and approximation, provides an objective measure of readability, and makes it possible to establish fixed standards for readability and quickly analysis. It provides immediate response. Greentext is based on research. The limitation of human working memory is central (Greentext 2012). Greentext can be used to see if a text is adapted to its recipient group.

When analysing, Greentext allows choosing between five recipient groups. The five recipient groups are adult private person, artisan, office employee, technical advisor and specialist. By dividing the potential recipient group in this way one has a unique opportunity to see which group the Council targets in their documents. The five recipient groups are divided by quantitative readability criteria.

By using the colour-codes, red, yellow and green Greentext gives an analysis of the document linguistic quality. Red means poor linguistic quality and yellow means that the linguistic quality is still in need of improvements. If the document complies with the recipient group,

the colour code turns green and the document is ready to be published. Only three of the recipient groups are used in this paper. The three groups represent three different layers of the population in terms of education and work. In general, this says something about their anticipated ability to understand and read complex texts.

*Table 8. Recipient groups*

Recipient group		Quantitative readability criteria
1	Adult private person	Recipient is not used to reading nonfiction. It requires a more readable text. In work mode, this receiver belongs in one of the other beneficiary groups, but as an adult private individual this person is not used to read complex nonfiction.
2	Office employee	In this group, there are individuals with some theoretical education but reading nonfiction is not an essential part of their job.
3	Specialists	Reading non-fictional texts are essential part of the job. These individuals have high theoretical education. Can read and understand the meaning of complex texts.

(Greentext 2012).

## 5.4 Availability

Drew and Nyerges (2010) have found that availability may be characterised with two criteria. The first criterion is the ability of citizens to request and receive governmental documents, and the second criterion is the capability to provide two-way access to information.

As a tool to make documentation more available information and communication technologies are increasingly being used. Particularly the World Wide Web (www) is frequently used. All over the world, various initiatives to provide public information and services to the public online, take place. It is possible to include the whole population in decision-making by making websites available and user friendly. When sites are correctly

designed, developed and edited, all users can have equal access to information and functionality.

*“An accessible website provides the same functionality to all, regardless of platform, browser, device or handicap” (DIFI 2013).*

Usability and quality are closely related. Usability is about how the website communicates and makes the information available to the recipient. Does he/she find what he/ she is looking for?

Hearings and open meetings ensure a two-way access of information.

In this section a set of criteria, that can be used to evaluate the availability of a website, published by Agency for Public Management and eGovernment (DIFI) have been adopted and adapted to this thesis. This means that some of the criteria has been omitted because they were of a technical nature, others left out because they are evaluated elsewhere in the framework. The set of criteria developed by DIFI is based on accessibility, customisation and useful content of the website. Both the ability of receiving and request information, and the promotion of two-way access to information are evaluated. Access to open meetings is also evaluated in this section.

*Table 9. Criteria used to evaluate availability A) Accessibility*

Accessibility:		M	P	N
1	Links stand out to normal text			
2	The website explains how to change font size			
3	Contrasting colours of font and background			
4	Text to speech function			

Table 10. Criteria used to evaluate availability B) Customisation

Customisation:		M	P	N
1	Content is marked with date on all relevant information units			
2	Satisfactory search engine			
3	The content is presented in other languages than Norwegian			
4	Printing is easy			
5	Descriptive pages, titles and addresses.			

Table 11. Criteria used to evaluate availability C) Useful content

Useful content:		M	P	N
1	Access to post journal			
2	Access to meetings			
3	Facilitate hearings – anyone who has an interest in a case should be given the opportunity to provide input to the matter.			
4	Ability to submit forms electronically			

## 6. Study design and method

In this chapter, the basis for choice of method and search strategy is explained.

Generalizability, reliability, validity and ethics are described here. Ranjit Kumar's "*Research methodology, a step by step guide for beginners*" is used as a reference in this chapter.

### 6.1 Background for choice of method

Essential for the method used was the invitation to evaluate if the ambition of an open/transparent process has been reached (Chapter 2), and curiosity about the process of ensuring transparency. Qualitative methodology was selected for this work. Qualitative research brings out the characteristics of a process and in depth description of the case at hand. This study has a lot in common with a case study. A case study is a useful design when exploring an area where little is known. The case selected becomes the basis of your research, and is carefully studied in an intense and holistic manner (Kumar, 2011). However, this study, because of its evaluating nature is an evaluation research. An evaluation research is a process of reviewing an intervention or programme for its efficiency, effectiveness and and/or appropriateness. An evaluating research has the ability to understand current practise, answer questions about the appropriateness of a service and it gives service providers not only an insight of efficiency, but also a possibility to change and improve.

The focus of the evaluation and the philosophical base that underpins an evaluation are two different evaluation perspectives that may be used to classify the evaluation at hand (Kumar 2011). The focus of the evaluation perspective looks at programme intervention, process/monitoring, impact/outcome and/or cost-benefit/cost-effectiveness evaluation. The philosophical orientation of the evaluations may be goal centred, consumer-oriented, improvement-oriented or holistic-oriented. The study performed in this thesis is a process evaluation. A process evaluation looks into the process of a service. By determining whether or not the original intentions with a service is consistent with the delivery, a process evaluation finds weaknesses and strengths within the service process (Kumar 2011). However, the two perspectives of evaluation studies are not mutually exclusive, and the evaluation in this study is also an improvement – oriented evaluation. Improvement-oriented evaluations focus on context and process aiming at making it more efficient and effective (Kumar 2011).

There are many aspects and perspectives that could have been the objective of an evaluation study. The Council use several tools to promote transparent decisions (Chapter 3.3.2). The only tool taken into consideration in this evaluation is the Council's website. This thesis is limited to evaluate the transparency of limit setting decision in five cases, but it is acknowledged that there are also other considerations that determine if a decision is truly accountable than only its transparency. Despite the fear that an evaluation study may reveal service inefficiency and that as a result a service may be closed down, there are many good reasons to conduct a process evaluation. Evaluation can provide data on whether a service works, and why, and which parts are effective, and why. It gives immediate feedback, and allows making changes instantly. Evaluation gives valuable information to use for long-term strategic improvements and planning. This aspect of evaluation examines whether the service provided (decisions) is transparent. This involves creating a list of indicators (in this case develop a framework for transparency) that need to be measured. The results will help to identify the strengths and weaknesses of the process, and where improvements may be made.

## 6.2 Sample and procedure

Purposive, strategic sampling based on the goal of this research was used. The five cases evaluated were carefully selected. The source was the website where the cases was published. The question of the fairness and legitimacy of decision- making, most typically come up in relation to recommendations/decisions that limit the availability of a medical treatment or service. Between 2007 and February 2013, the Council has recommended limit setting decisions, which means that one has not implemented expensive treatment - despite the fact that some patients *could have* benefited from it (Ringard et. al 2012). Accordingly these cases, that clearly states a rejection of a treatment (relatively few) have been the focus. The cases have been read, and in each case the background information, important questions the vignette sets, process and rationale for decision have been written down (Chapter 7). To evaluate the cases transparency the framework for transparency has been used (Chapter 5)

However, the cases are not the only focus. The actual website, where the cases are published, have also been evaluated.

## **6.3 Reliability, validity, generalizability and ethics**

The reliability (trustworthiness) in research studies is of great importance. Reliability means that doing the same research repeatedly will give you the same result. If one by using the same instrument (in this case the transparency framework) in the same situation and get the same result the research is reliable. To ensure reliability, the framework is easy to understand and acquaint oneself with. All the information of the Council work, the cases evaluated and the website is referred to and easy to find.

Validity refers to whether the researcher has measured what he or she wants to measure (Kumar, 2011). Validity can be divided into internal and external validity, where the internal validity is described as the degree of credibility in the study, while the external validity is described as transferability of the study's results. This can be understood as generalization of the results and conclusions from a study (Kumar, 2011). In creating a credible and logic link between the research question and my study object, I have tried to establishing validity. This implies a justification of each question in relation to the objectives in the study. It is also important to demonstrate that the questions asked actually are measuring what they intend to measure. When it comes to the generalization of the study it is two folded. The framework for transparency is designed in a way, so that it is easy to understand and use for any organization that wants to evaluate their level of transparency. It is designed for organizations and individuals that wish to make their decisions transparent and available. Any organization that wishes to use this framework in evaluating the degree of transparency in their decisions can adapt and adopt the frameworks criteria and values so it fits their context.

This study is a small assignment in a large and extensive field. The design provides on a general level an in-depth understanding of how to ensure decision transparency, but the study's conclusion can only be used in the context of the Council and is not generalizable.

Throughout the process of writing this thesis I strived to follow ethical considerations. In 2011, I had my internship with the secretary of the Council. In this time, I got to see how the secretary works up close. I was very well received and got to know the people who work there. I have tried not to let this time, or my acquaintance with the Secretariat in any way impair or bias my work.



## 7. Five limit setting cases

This chapter presents five cases that have been evaluated with the framework for transparency. The cases are described with background information, important questions the vignette sets, process and rationale for decision.

The cases are presented here in the order they have been up for discussion in the Council. The oldest documents first, the most recent last.

A: Cochlea implant – 2007

B: Transcatheter aortic valve implantation – 2008

C: Monoclonal antibodies – 2008

D: Vaccination against rotavirus infection – 2012

E: Postpartum depression – 2013

### 7.1 Cochlea implant

#### **Background:**

Cochlea is a spiral shaped cavity of the inner ear that resembles a snail shell and contains nerve endings essential for hearing. A Cochlear implant (CI) is an advanced and relative expensive, small electronic device. It aims to regain or improve hearing for people who are deaf, or who have so poor hearing that hearing aids have little or no effect. Through surgery, electrodes are placed in the cochlea and sound is directly transmitted to the hearing nerve. This technique relies on the hearing nerve still functioning. Better ability to communicate, improve sentence comprehension and quality of life are benefits of using CI. In Norway, hearing impaired has the right to one cochlea implant, but are not entitled to two (Nasjonalt Råd 2013 A).

### **Important questions the vignette raises**

The main question in this case was if hearing impaired should have a right to a second CI?

### **Process**

In spring, 2006 the Council conducted an economic evaluation of CI. A knowledge and cost impact analysis was finished in November the same year. This research could not say anything definite about the effect of two versus one implant. The issue of whether a second implant for deaf adults is covered by the priority regulations definition of “right to necessary health care” was discussed by the Council (Nasjonalt Råd 2013 A).

### **Rationale for decision**

The Council support that patients with correct indication is entitled to only one cochlear implant. The Council believes that many can benefit from two implants, but the costs in relation to the effects (efficiency condition) implies that one cannot prioritize this at the present moment (Nasjonalt Råd 2013 A).

## **7.2 Monoclonal antibodies**

### **Background**

In 2006 3586 people was diagnosed with colorectal cancer. It is the second most common cancer in Norway. About half of all patients with colorectal cancer will have metastases during the course of disease. More than 1,600 people die from this cancer every year. Survival at 5 years is less than 60% for the whole group. With metastasis it is only 10-15% chance of surviving 5 years. In addition to surgery and drug therapy, radiation therapy is an important treatment option for patients with metastatic colorectal cancer (Nasjonalt Råd 2013 B). There are currently two types of monoclonal antibodies that are approved for metastatic colorectal cancer. The two products differ slightly from each other in terms of how they work (Nasjonalt Råd 2013 B).

### **Important questions the vignette raises**

The main question was whether monoclonal antibodies should be included in the standard treatment of metastatic colorectal cancers. The monoclonal antibodies will not be replacing current treatment regime, but will be in addition to these.

Issues of concern were the very high costs associated with these drugs, and the incomplete documentation of clinical effect (Cost effective condition) (Nasjonalt Råd 2013 B).

### **Process**

HDIR raised this case. A vignette was presented in a meeting 26 March 2008. More background information was needed in order to make a decision, and the case was sent back to the Secretariat. The Secretariat presented the case for the second time in a meeting 8. September 2008. The council concluded not to recommend making use of monoclonal antibodies as a part of the standard treatment of patients with metastatic colorectal cancer (Nasjonalt Råd 2013 B).

### **Rationale for decision**

The Council recognizes that metastatic colorectal cancer is a serious disease with high mortality. The expected treatment costs do not appear to be reasonable in relation to the cost effectiveness. This means that the prioritizing regulations last paragraph, cost effectiveness, is not fulfilled (Nasjonalt Råd 2013 B).

## **7.3. Transcatheter aortic valve implantation**

### **Background**

The aortic valve release blood into the circulation system when the heart contracts. When the heart is filled with blood the flap prevents that blood flows back. The main indication for replacement of the aortic valve is aortic stenosis, i.e. narrowing and stiffening of the aortic valve. Over time, this can lead to enlargement (hypertrophy) of the ventricular muscle mass and development of heart failure. Aortic stenosis generally appears as a progressive condition in which the heart must work harder to maintain normal circulation.

Severe symptomatic aortic stenosis is usually treated with surgery, where the heart valves are replaced. The surgery requires general anaesthesia and use of heart lung machine. For the

majority of patients this open-heart surgery is considered as a safe procedure with good short- and long-term results. However, there is significantly increased operative risk in old age and accompanied disease (comorbidity). Transcatheter aortic-valve implantation (TAVI) has been suggested as a less invasive treatment for high-risk patients with aortic stenosis. TAVI is a new procedure, in which a bio prosthetic valve is inserted through a catheter and implanted within the diseased native aortic valve (Nasjonalt Råd 2013 C).

### **Important questions the vignette raises**

Is TAVI a treatment that should be offered to patients as part of “necessary medical care” in Norway?”

### **Process**

The introduction of TAVI in Norway was controversial. Feiringklinikken treated ten Patients in 2008. After two postoperative deaths, the operations were halted. NOKC concluded the same year that the method was promising, but the documentation of clinical efficacy and safety was limited. The case was introduced to the council in a meeting in late march 2008.

### **Rationale for decision**

The case was presented with documents from NOKC, letter to the Norwegian Medical association from the Council, submission from the Norwegian Society of Cardiology, submission from the Norwegian Radiology Society and a submission from Norwegian Society of Thoracic Surgery. The Council stated in 2008 that TAVI was an experimental treatment and recommended that any treatment with this surgery, should be in form of inclusion in clinical trials and not as part of standard treatment (Nasjonalt Råd 2013 C).

## **7.4 Vaccination against rotavirus infection**

Rotaviruses are the most common cause of severe diarrheal disease in young children throughout the world. In Norway, even though the virus is rarely fatal, it causes up to 10.000 visits to general physicians, and about 900 children are admitted to hospital each year. Two oral rotavirus vaccines, Rotarix and RotaTeq are available in Norway. Both vaccines are considered safe and effective in preventing gastrointestinal disease caused by rotaviruses. In

2007, the World Health Organization (WHO) recommended the inclusion of rotavirus vaccination into national immunization programme. If the vaccine becomes a part of the childhood immunization program, the vaccine will be offered to all children between 6 and 32 weeks in Norway. In total, about 60.000 babies each year (Nasjonal Råd 2013 D).

### **Important questions the vignette raises**

A Vignette was put forward to the council at a meeting in February 2012. The main question is whether the vaccine against rotavirus infection should be recommended or not. In addition, this case affects a number of related issues. The value of parents labour, if there are other vaccines that should be prioritized into the childhood immunization program instead, the trust of the immunization program and the possibility to secure sufficient resources are all questions that was discussed in this case. In addition to the extent to which this vaccine can be said to meet the different criteria, severity, efficacy and cost-effectiveness (Nasjonal Råd 2013 D).

### **Process**

The Norwegian Institute of Public Health (FHI) sat up a broad-based working group in 2006. This group should assessed whether or not the rotavirus vaccine should be included in the Norwegian childhood immunization program or not. In autumn 2011, the group put forward its report "Recommendations on the use of rotavirus vaccine in Norway" (Anbefalinger om bruk av rotavirusvaksine i Norge). The group recommended that the vaccine should be implemented. Health economics was considered, but primarily it was the technical aspects of the prevention of rotavirus disease in infants, which formed the basis for the recommendation given by the working group (Nasjonal Råd 2013 D). The vaccine was not implemented in the vaccination program. In a letter from HOD to NC dated 07.12.12, HOD wants the council to look into the matter (six years after the first report). The council wanted this case to be further evaluated, and in June 2012, the case was presented.

### **Rationale for decision**

Representatives from the Norwegian paediatrician Society, Division of Communicable Diseases and The Norwegian Nurses Organization's (NNO's) each held a presentation at the meeting in February. In addition, members of the Council got the report of FHI's work group and comments from the minority of the working group, the summary of the health economic

evaluation, a Cochrane review and a letters from the pharmaceutical company. The majority of the council does not want to prioritize this vaccine ahead of other initiatives in health and care giving sector.

The rationale for the decision was taken with regards to the priority regulations. When rotavirus cannot be categorized as a “serious” illness, this vaccine should not be prioritized before other important health actions (Nasjonalt Råd 2013 D).

## **7.5 Postpartum depression**

### **Background**

The early development of infants takes place in close interaction with the immediate caregivers. Parents' mental health is important for baby's development. In Norway, it is estimated that as many as ten per cent or more suffer from post-partum depression. The post-partum depression-screening test used in Norway is called Edinburgh Postnatal Depression Scale (EPDS). EPDS has been translated into 25 languages, including Norwegian. The test consists of a form with 10 questions where each answer gives a score. Women who achieve high scores will be followed by a thorough clinical evaluation before a depression diagnosis can be made (Nasjonalt Råd 2013 E).

### **Important questions the vignette raises**

Is there sufficient evidence to support efficacy and cost-effectiveness of screening for postpartum depression? Do we know enough about the Edinburgh method to recommend it in Norway? Could there be other methods that are more targeted and effective (Nasjonalt Råd 2013 E)

### **Process**

On behalf of HDIR, a National Competence Network for infants and small children mental health was established in 2006. In their mandate the youngest children and their mental health was emphasized. It was this network that initiated postpartum depression screening. Training in mapping and implementation of mapping tools was encouraged. In 2007, the method was initiated in six municipalities. Training includes the use of EPDS, and a further follow-up of the women who need it.

### **Rationale for decision**

Screening for postpartum depression with the EPDS does not meet the WHO's criteria for when to conduct a screening. National Council recommends that screening for postpartum depression is not established as a national offer at the time of the discussion (Nasjonalt Råd 2013 E)

## 8. Evaluation and findings

In this section, the evaluation and findings are presented. All the cases had similar results in the criteria contextual *integration* and *standardisation*, therefore the findings are only presented once, but all cases have been evaluated up against each criterion. For the criterion *clarity*, each case is presented individually as the linguistic quality varied from case to case. The criterion *availability* assesses the availability of the website.

### 8.1 Contextual integration

A contextual overview of the five cases in this thesis is important to get an idea of the "big picture". In providing sufficient information and references, stakeholder is able to not only know about a decision and its rationale, but also able to find the information to justify that the decision is taken on proper premises and for the right reasons.

#### 8.1.1 Decision fully justified

When it comes to fully explain the rationale behind the decision, the Council fails. Only fragments of the discussion in council meetings are cited in the text. It is not stated explicitly how the different parameters have been weighted against the other, or what was stated by each member of the council in the discussion.

#### 8.1.2 Background information provided

In describing the essential background information the Council does an adequate job. Each case has a case presentation (saksfremlegg). Both medical information of the procedure and problems present in each case is described in the presentation. Even though the different cases differ slightly in the quality of the background information, all over this is well covered and it is easy to understand both the medical treatment at hand, and the priority dilemma.

#### 8.1.3 Different alternatives

Cases treated in the council are placed in one or more of 6 different categories. All of the five cases evaluated in this thesis belong to the category "Introduction of new technology". TAVI is also placed in "Distribution of health services".



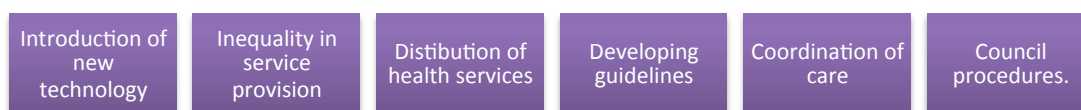


Figure 5. Six case categories

### 8.1.4 Consolidated document

All cases have a consolidated document, which gives a summary of the case. A consolidated document has three sections: a quick introduction to the background, rationale for decision and the actual decision. A table of contents with vignette, background information, presentations and “what happened after the decision” is provided. Additionally the contact information to the secretary, an employee responsible for the case and case proposer is listed.

Table 12. Evaluation of the Contextual Integration

	Questions	M	P	N
1	Is the decision justified?		X	
2	Is background information provided?	X		
3	Are different alternatives to the decision available?		X	
4	Is a consolidated document provided?	X		
5	Are there citations in the text?			X
6	Is there a reference list?			X
7	Is there a list of abbreviations?			X
8	Are there a table of contents?	X		

## **8.2 Standardisation**

Standards streamline and simplify. They exist in many areas and are used in many different situations in modern society. Standardisation is about the process of when a need or an idea occurs until a standard is completed (Standard.no 2013).

### **8.2.1 Follows routines and a defensible plan**

Neither routine nor plan for how the Council tend to achieve the goal of transparent decisions is described on the website. (This does not mean it doesn't exist).

### **8.2.2 Follows processes that are consistent, standardised, formalised, flexible and expandable**

The case processing (Figure 6) starts by defining a problem. Anybody may propose cases for processing. The secretary, in dialogue with proposer, carries out an assessment of the issues raised by each case. The objective is to give a well thought through advice in response to the problem. The case is presented to the council members in a two-stage process. First, a short written presentation (a vignette) is provided. Based on the vignette the council members make a decision on whether to proceed with the matter or not. If the members decide to proceed with a case, the secretary investigates the case further. Second, the case is presented in another council meeting after a more thorough investigation. The investigation ensures that the members have an adequate basis in all relevant facts to make educated decisions, and give further to give advice to the authorities. Options and consequences are looked for and discussed, before a decision is made. The implementation is not in the council hands.

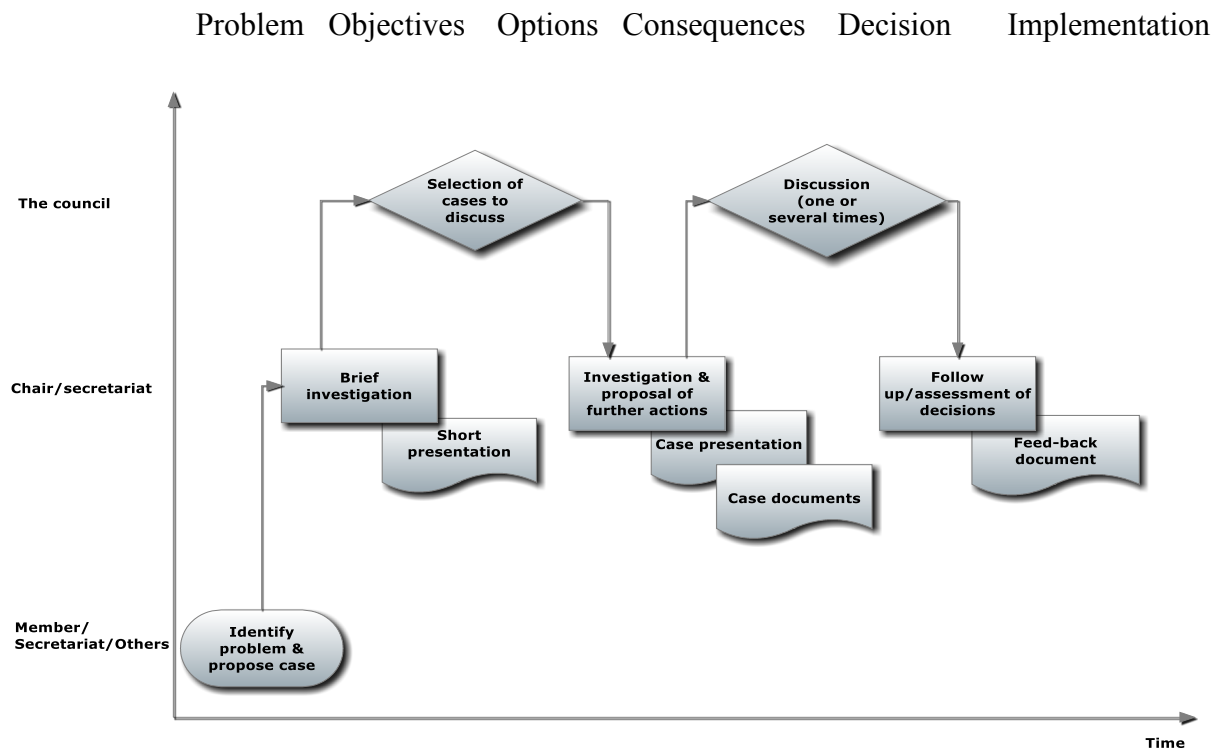


Figure 6. The Council's Case process (Ringard 2013).

As mentioned earlier the cases are divided into three groups, cases for debate, informative cases and case themes. Cases for debate demand that council members have looked into all relevant aspects. Members should have made up their mind about the matter before council meetings. The aim of debate is to look into the different angles of the case and arrive at a decision in a deliberative manner. Some cases are considered over several meetings. Once the council arrive at a decision, responsibility for the decision is passed on to others. Cases for information are cases where council members are presented with information on relevant issues. Normally no written information is given in advance. When it comes to theme cases, there is often issued a vignette in forehand. Theme cases are making use of a comprehensive briefing, usually involving stakeholders with different points of view. The objective is to identify elements that are suitable for one or more future cases (Prioritysetting.no 2013). All cases handled in this thesis have been cases for debate.

Each case is categorized in relation to how far the council has come in the decision process. No specific time is set for a case procedure. Some cases may be complex and of such different character than other cases, and thus more time demanding. However, generally speaking, delay in the proceedings must be justified (Public Administration Act 1967).



*Figure 7. Location of a case in process*



*Figure 8. Location of cases not approved*

### **8.2.3 Users are able to track decisions over time**

The secretary will follow the case if possible, implicit, it is possible to follow some cases over time.

### **8.2.4 Takes the priority conditions into consideration**

As the last (but perhaps the most important point when it comes to priority setting decisions), this framework evaluates whether the decisions taken, is in accordance with the general principles and prioritisation conditions.

The principle of equality and quality of the services provided is important when it comes to the overall goal of the health service. Conformance to the priority conditions set by Lønning II, is one way to ensure that differences in service provision do not evolve. Making the right priorities is a way of ensuring good qualities in services. This way, if the conditions for priority are taken into consideration in decision - making, one may be one step closer in ensuring both services of high quality and equal service provisioning in health care.

In all five cases the conditions *severity*, *efficiency* or *cost effectiveness* is mentioned, but not explained. Thus the reasoning behind the decisions is not justified (ref. 8.1.1).

Table 13. Evaluation of a Logic and Rational decision – making process

	Sub objectives	M	P	N
1	Follows routines and a defensible plan	x		
2	Follows processes that are consistent, standardized, formalized, flexible, expandable	x		
3	Allows users to track decisions and policies over time		x	
4	Takes the priority conditions into consideration		x	

## 8.3 Clarity

Clear and understandable language is a prerequisite to achieving transparency. Hence, sentences, paragraphs, document sections, or all documents given in a case, could have been evaluated when it comes to degree of clarity (Drew and Nyerges 2010).

In all of the five cases evaluated in this thesis, a text is presented with the headlines: *Original proposal*, *early discussion*, *discussion* and *final decision*. This text has been the object of my analysis in Greentext. The reasons for this choice are several. First of all, this text is the first that meets the eye in each case. It is the introduction to the Council's work and decision process in each case. Second, the text provides a summary of the decision path, and serves as a communication tool for the public aiming towards an explanation of the problems discussed. As such, it should give stakeholders sufficient information to understand the decision at a profound level. Third, the Council's secretary writes the texts. Difficult words and sentences that are used in this text are likely to be found elsewhere in the case documents. This means that the linguistic jargon used, most likely, is representative for other similar texts and

documents published on the website. "Greentext" was used to evaluate if a document is reader friendly or not, without attempting to make any changes.

*Adult private individual, office worker and specialists* are chosen as the target levels of understanding i.e. groups, in the evaluation of clarity. The figure shows (from right) the different texts analysed with individual adult, office worker and specialist in mind. The upper line is showing the documents linguistic quality in full. The next line is an indicator of the length of the words. If there are many difficult and long words this line will be red. The next line is saying something about the length and structure of the sentences. The last line shows the variation in the language. Are there many repetitions, making the text above boring to read, it will appear here. Together the indicators say something about the textual linguistic quality.

The results from the analysis in Greentext are shown in figure 9,10,11,12 and 13.

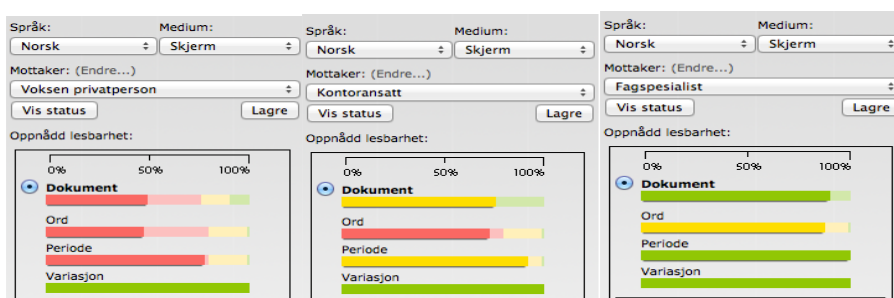


Figure 9. Recipient analyse - Cochlea Implant

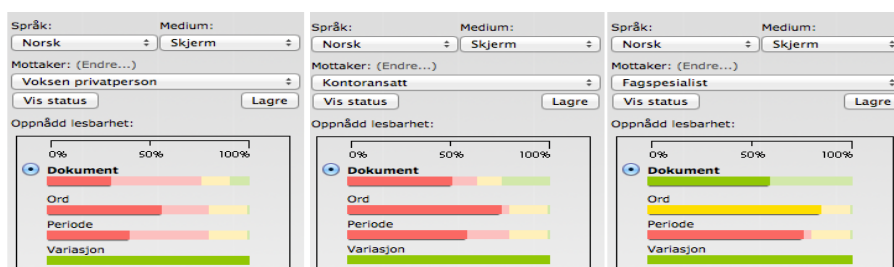


Figure 10. Recipient analyse - Transcatheter aortic valve implantation

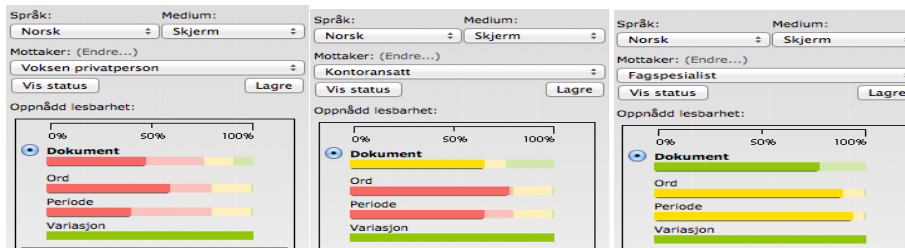


Figure 11. Recipient analyse - Monoclonal antibodies in cancer treatment

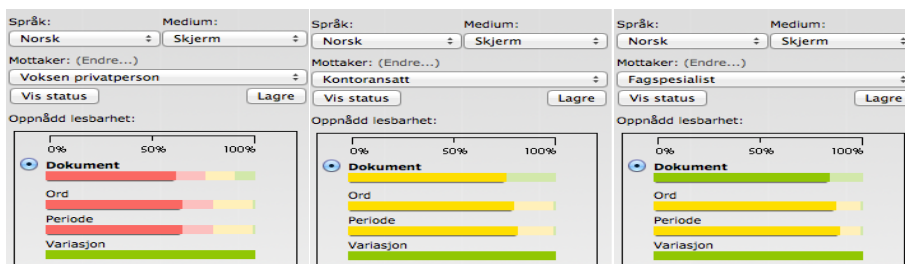


Figure 12. Recipient analyse - Rotavirus

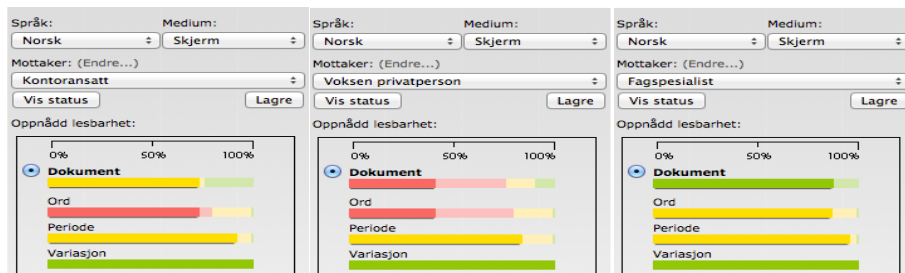


Figure 13. Recipient analyse - Post partum depression screening

By looking at the colour codes one might say, on a general level, that more education increases a person's ability to read and comprehend these documents. Considering the *adult private person* target group, the documents are characterized by long words and sentences. When *office worker* is a target, the colours often change from red to yellow. The texts are still difficult to read, but is not *as* inaccessible. Words as well as periods remains consistently too long. By analysing with specialist as a target group the texts are significantly more accessible. This means that documents makes little sense to ordinary people, and are best suited for people with high education. All texts are characterized by long sentences and difficult grammar terminology. However, the variety of the language is very good. All texts analysed

for a specialist gets green light for the document as a whole. The texts that are of more recent date are more reader friendly for all three groups in all of the five cases.

## **8.4 Availability**

The Council's website is the main tool to make the priority setting cases available. The same website is also the place to find other general information about the Councils work.

The criterion *availability* has nothing to do with the evaluation of the cases or their descriptions, but considers the website where case documents are published. Specifically this means an evaluation on the website's functionality and design with respect to user-friendliness and ability for the users (citizens) to request and receive government documents. The population of Norway is multi-faceted and multi-cultural. Is the website well suited for different kinds of users, such as the visually impaired, blind or people who do not speak Norwegian?

### **8.4.1 Accessibility**

*Accessibility* evaluates if links clearly stand out (easy distinguishable) compared to normal text, that it is clear to the user how to change font size, contrasting colours of font and background, and easy-to-find-function for the user to convert text to speech.

When it comes to the website and its accessibility, it falls short evaluating against some of the criteria in the framework. While links stand out compared to normal text, and there are contrasting colours of font and background, the website does not explain how to change font size, nor does it provide text to speech functionality.

### **8.4.2 Customisation**

Technologies such as the Internet enable the customization of services. Upload/publication date of the content, a satisfactory search engine, different languages, easy printing and descriptive pages and titles are evaluated to see if the Council's website is open to customisation and facilitates easy navigation. The evaluation descriptive pages and titles are fine, but content is not marked with dates, making it hard to tell what information is old and what is more recent. The search engine available is easy to use and clearly visible. However,



when searching for cases, all information that contains fragments of the search word pops up. When it comes to presenting the content in other languages than Norwegian, it falls short. Even if there is a website in English, “prioritysetting.no”, only fragments of the website and case documents are translated. Printing case documents is not easy. In fact, if it is desired to print the consolidated document, it is necessary to copy and paste the text into a word document several times to get both the earlier discussion and the decision printed on one page. Every page has descriptive titles and web addresses.

### 8.4.3 Useful content

In this context, *useful content* means that you find the information that you are looking for, and that this information is accurate and complete. This means that **all** the documents in a case, and not only case documents, but also e-mails, letters etc. should be available through a posting or submission journal. Access to case meetings is important, in addition to hearings where stakeholder may have a say in the case preparations, and also the ability to submit forms electronically.

A posting/submission journal is a place where all mail in and out of a case is published; this may be the case suggestions, e-mail, letters etc. Posting journals are not provided in either of the cases evaluated in this thesis. The council meetings are, as mentioned above, open to the public, everybody interested in a case may come to a council meeting. Hearings have not been facilitated in any of the five cases. It is possible to submit the case proposal electronically.

Table 14. Criteria used to evaluate availability A) Accessibility

	Accessibility:	M	P	N
1	Links stand out to normal text	X		
2	The website explains how to change font size			X
3	Contrasting colours of font and background	X		
	Text to speech function			X

Table 15. Criteria used to evaluate availability B) Customisation

	Customisation:	M	P	N
1	Content is marked with date on all relevant information units			X
2	Satisfactory search engine		X	
3	The content is presented in other languages than Norwegian		X	
4	Printing is easy			X
5	Descriptive pages, titles and addresses.	X		

Table 16. Criteria used to evaluate availability C) Useful content

	Useful content:	M	P	N
1	Access to post journal			X
2	Access to meetings	X		
3	Facilitate hearings			X
4	Ability to submit forms electronically	X		

## 9. Discussion

A search showed significant gaps in the literature when it came to defining transparency. To be able to answer the research question it was therefore necessary to develop a transparency framework. The result as presented in this thesis presents a supplement to the original framework and is meant to serve as an instrument to ensure that prioritization decisions are public, transparent and accessible.

In this chapter the different criteria in the Transparency Framework (availability, logic and rational, integration and clarity) is discussed and the findings evaluated. The shortcomings in theory, the methodology, and the challenges concerning the Transparency Framework are also covered.

### 9.1 Study objective

The initial objective of this study was to find out if the Council has reached its goal in making the process of decision-making and its rationale transparent. A framework that could be used to support this work was not found. The literature search made it clear that such a tool did not exist, or at least could not be easily found. Transparency seems to be something nebulous that everybody attempts to achieve, but nobody really knows what it entails or how to implement it in practice. Therefore, the lack of criteria when evaluating transparency made it necessary and inherently useful to develop such a framework. The literature study did not reveal any previous studies with this this kind of approach. This is probably the first time a framework for evaluating transparency in a limit setting decision process in healthcare has been developed.

There were two main reasons why the Council was (re) established in 2007. One reason was that they wanted a meeting place for stakeholders who carry major responsibilities within the healthcare sector. The Council has five annual meetings where these stakeholders, as well as user groups are represented. Deliberation can be with only one person, but as previously described, in the example analysed in this thesis, a deliberative discussion was held among a closed group of individuals, the deliberative elite (Barisione 2012). The Council members come together to discuss different angels of a case. The different sides are carefully and seriously weighted against each other. The deliberative discussion reflects the fact that

Norway is a democratic country where there is tradition for allowing all opinions to weigh equally. Through persuasive arguments and presentation of evidence the Council members should be able to make a rational choice. This way deliberation is used as a strategic methodology to promote knowledge-based research in decision-making (Gauvin 2011). By having open meetings where all who wish to, can come and listen to the discussion, the Council shows that they intend to make good and right decisions. In addition, they emphasize that they have nothing to hide from the public, and that there is no hidden agenda or dirty games. By making the process of how priorities are made more visible, stakeholders may get a more realistic insight. A wide and all-inclusive debate on the issue is allowed. The decision becomes socially robust and not immediately challenged by public voices on the basis of information gaps (Kaiser et al. 2006). By the participation of both experts and decision makers, research and decision-making is connected. One can therefore say that the goal of creating a meeting place is reached.

The second reason for (re)establishing the Council was that it was desirable to give decision makers greater legitimacy in prioritization decisions where one limit access to health care. To achieve the goal of greater legitimacy and accountability the Council has chosen to use publicity and transparency as key instruments. The main strategic tools they have adopted to achieve the goal, are open meetings, deliberative discussion, and a public website. This paper has taken a closer look at how available five limit setting decisions are for the public. Findings in this paper suggest that the Council has unused potential when it comes to making their decisions transparent.

## **9.2 The publicity condition**

A4R has been rapidly gained worldwide acceptance, and is regarded as a decisive breakthrough, but the reactions to the publicity condition is not undisputedly positive. The condition, as it appears in the framework of A4R, is vague. A4R states that public disclosure is important and appropriate when it comes to just decisions in health care, but nothing is said about how this should be or what it takes for something to be categorized as public and available. Daniel and Sabin state in their book "Setting limits fairly" (2002), that it is not necessary with criteria for public availability. Different organizational structures are able and entitled to figure out how they want to do this themselves. However, after reading through relevant literature, it is clear that this is not true. In practice health care organisations value

public access and transparency differently. The lack of criteria makes the publicity condition unclear, and different organizations have different interpretation on what open and transparent decision-making consists of. Successful priority setting is a desirable goal for decision makers, but they struggle to set priorities appropriately, particularly because they lack consensus about which values should guide their decisions. The result is an unlike practice in how and how much is published from organisation to organization, even within the same health care system.

In decision-making, there are several advantages in making the process for “how and why” public and accessible. On a general level, priorities in health care are of collective and not only of individual interest. Alternative ways of spending money on culture, education, research etc. makes limit setting decisions affect us all (Det etiske råd 2013). In the allocation of collective resources, publicity ensures citizens right to monitor and protect their interests. Publicity implicitly means that it becomes a requirement that decision makers justify their choices. It may be easy to take shortcuts in a complex decision making process, where reaching and providing decisions are difficult. Decisions based on personal interests or intuition are avoided by publicity because a public decision process does not leave any room for shortcuts, thus, speculation in the background for decision is avoided. By making decisions public and consistent across cases, a classical requirement of fairness is promoted. In addition, the principle of equality is promoted by publicity, because it makes it possible to detect unjust differences between cases.

There are many reason to have open decision-making processes, there are also counter arguments. Making difficult decisions in full publicity may have many drawbacks. Daniels and Sabin (2002) themselves draw attention to several objections. Negative response for decision -making bodies, loss of public trust and perversion of the application process is some of them.

Making decision public does not automatically strengthen legitimacy. Transparency may reveal incompetency, and lead to increased negative publicity and actually undermine legitimacy (Jones et. al. 2013). When the aim of transparency is combined with a fear of making unpopular choices, and to avoid blame, sensitive information may be tightly controlled and creative ways to evade culpability may develop. When the arguments for or against an issue become personal and you have public access, participants know that opinions will follow them throughout their lives. This can cause people to be more cautious in their

statements. An open discussion can make you afraid to make unpopular choices in fear of retaliation in the media and by stakeholders, and thus lead to bad policy (Jones et. al. 2013). Further, accountability is not automatically received by transparency. The organization may make the information accessible fit the demands of transparency without disclosing the real internal workings of the organization.

This being said, transparency is important because it is closely linked to people's right to know, to control the public administration, and to have the possibility to publicly discuss important issues based on relevant information and correct facts.

## 9.3 The framework

How the Council is advertising their cases and meetings is not given much attention in this thesis, but it goes without saying that if the documents should be public, the public must know that they exist.

Despite the fact that there is a growing trend that public documents are transparent, there is no framework for how to make sure that they are just that. The law is governing *what* will be public. *How* documents are made available is up to each organization to decide.

A framework for transparency with specific criteria, in limit setting decisions in health care, as developed and documented in this thesis, sets what is expected of a transparent decision-making into a system. Adhering to this framework will make it easier to understand what a transparent decision is, and how to ensure that a decision actually is transparent. The principal ideas are that for a decision and the background for the decision to be defined as transparent, it must be a contextually integrated, as well as a standardised, clear and readily available decision. This framework probably has shortcomings that are not known as of yet. After all, it is the first time such a framework is developed, and it has not been sufficiently used in practise.

### 9.3.1 Contextual integration

The evaluation of the cases in this this thesis show deficiencies related to integration and how the decisions fit into the “big picture view”.

Integration in this case is defined as having relevant case references to other sources, a good reference list, a list of abbreviations, and a table of contents in each and every case. This does not only make it possible for the stakeholders to understand a many sides of case profoundly, it strengthens the case's verifiability. Further, with this approach the Council appears accountable and not afraid to be challenged on their rationales for decision-making. In integrating the cases, the Council provides the recipients with a background document, a consolidated document, and a table of content.

The main reason that the Council wanted open decisions was that one wanted to avoid speculation about what was said at the Council meetings. It is not required in limit setting decisions, which often have large and complex documents, that all information is repeated in a summary. However, when it comes to fully explaining the rationale behind the decision, the Council fails. The information presented to the Council in each case is present, but only fragments of the discussion in council meetings are cited in the text. It is actually not expected nor desired that all concepts be fully explained. One major problem is that there are many abbreviations like QUALY, FOBT, FHI, WHO etc. In some of the cases, the abbreviations are explained in the background information, but in some cases, there is no explanation, and no referral to other sources that could explain the concept further. Thus, the text and case documents in that way only aims at recipients that are already familiarized with priority work and health economic concepts. When it comes to citations in the text, only two of the cases refer to other sources. The case of CI provides us with links that are no longer in use, and in the case of MA there are many references to other cases in the consolidation, but from the information in the text, numbers, it is impossible to find those cases by using the search engine on the Council's website.

Enough information should be presented so that readers understand the decision and that its broader context is also understood. The summaries are of varying quality, but all over the description of the discussion is not sufficiently detailed and it is therefore difficult to understand the reasoning behind the decision by reading the summary.

Different alternatives are not presented in all of the cases. The only place this criterion is fulfilled is the case of rotavirus. Here it is said that if the proposer could choose between vaccine against Rotavirus and vaccine against Hepatitis B, he would choose the latter. However, in all cases, the reader gets very little information about what is prioritized, or what

could be prioritized instead. Sometimes the reader may get a rather vague understanding or suspicion that the resources could be better spent elsewhere.

The cases submitted to the Council, often is of such a nature that they rarely have similar cases to be compared too. The Council categorise the cases, but even if the cases are in the same category, they are of a very different character.

### **9.3.2 Standardisation**

One can ask why a logical and rational plan is important. The basic purpose of planning is to improve the opportunities for reaching goals that would otherwise not have been reached. A good plan of how to work creates continuity and predictability. A good plan facilitates that similar cases are treated alike. The process of how to process a case in the Council is a well worked through plan. What is missing is how they actually find the evidence that they use as the rationale behind the decision. It is hard to see if it is the same procedure each time depending on the particular topic where the case is categorized under, or if it is up to the person responsible for the matter how they choose to proceed, investigate and find information?

The evaluation shows that the conditions for priority are an important part of the discussion in all of the five cases. Every case either direct or indirect refers to the conditions for priority. Some of the cases include all three prioritizing values, and some cases do not take into consideration more than one. It is not a need for discussing all conditions in all cases, since all three have to be present for a treatment to be prioritised. Like in the case with TAVI, if treatment is not effective, it does not matter if the illness is severe. What is missing in general when it comes to explaining the rationale behind a decision is what the different conditions imply and why they are referred to.

### **9.3.3 Clarity**

Linguistic quality has been evaluated. On a general level the more education a person has the more he/she understand of the content of case documents.

Language affects how available a decision is. Individual variables with the recipients are important, such as level of education and training in reading complex text.



The Council was created as a part of the government communication strategy. The aim was to create better understanding of how priorities are made in limit setting decisions in health care, and at the same time ensure a fair allocation of resources. On the one hand, one may say that since these documents are public documents as many people as possible should have access to them. From this point of view, the recipient group should be adult private person. On the other hand, this may lead to a great simplification of the language in such a way that content might change its meaning. Being clear in all cases at all time is not possible. The Council must often deal with complex issues, and there may be many reasons why they have to make reservation and use approximate expressions. The evaluation shows that the recipient group that most easily read and understand the documents are people with high education and experience in reading difficult texts. A simplification of the language, so that more people may understand the documents is important and appropriate. This being said, simplification should not lead to poor and oversimplified language. Not all texts can be simple, and not all texts can be free of jargon. In addition, making documents reader friendly to all will lead to major additional work, unnecessary amount of time will be spend on finding alternative words and phrases to already existing terminology. The challenge is to inform the public about the case in a way that is understandable, but at the same time make sure it does not lose its original meaning. What is important is that the document content is understood by the recipient, and if not referred elsewhere.

Greentext is a tool to objective analyse text. Length of words, sentences and the variety of words are evaluated. The intuitive understanding of what is actually said is not a part of the analysis. This way Greentext come to short in saying something about the content of the text, and if the message given is the message received by the recipient. However, Greentext may be used as an indicator of linguistic quality and as a tool to make improvements. It is important to point out that the only way to actually know if a text is understood is to ask the person that reads it.

#### **9.3.4 Availability**

When it comes to the availability of the five cases, the evaluation shows deficiencies. First webpage can seem bewildering with a lot of small print, although both fonts and the links stand out. Basic ingredients such as changing print size and text to speech function is not

present. The headings of each web page are descriptive, but when searching for cases it is random what documents appear in the search result.

When it comes to making documents accessible it takes more than posting them on a website. The web site's design and opportunities for personal adaptation is also important. The Council's work can be important to many people. Easy navigating, so that you can quickly find what you are looking for is important. The purpose of the website is that decision-making should be available. It is logical to assume that those searching for single words are after a decision and its case documents. It would have been appropriate if the result of the search had been sorted, so that the case and its documents came up first. Sometimes time must be spend to locate the page you wish to find.

To evaluate a web page's availability require knowledge of how a website is designed. In this context this is of technical nature and are not included as part of the framework. What is included is what is possible to detect by navigating on the website. A website is an organizations public face, and it need to be updated in a systematic manner. This is not done. Over time this can lead to the Council appearing unprofessional and out-dated.

# 10. Conclusion

The research question examined in this thesis is whether the Norwegian Council for Priority Setting in Health Care succeeded in its attempt towards transparent decision-making. An evaluation of five limit setting cases, and the website functionality was performed.

The evaluation showed some weaknesses. The potential for improvement is both simple actions such as ensuring that the reasons for an advice (ex a link to the conditions for priority and an explanation of each of them) and more resource intensive improvements like updating the website. Having an awareness of who you are writing for, and integrate documents with abbreviations, references and citations is an easy way to make decisions more transparent.

As an expert priority body, the Council has unused potential. In the case of depression screening for example, the method they wanted to use does not fill the WHO 's criteria for screening, and thus the condition for efficiency was not fulfilled. Therefore, this screening did not get priority. Here there one thing worth noticing. *The background information the council based its advice on is generalizable to similar cases.* This means that if other screening cases are discussed in the council – *or elsewhere* in health care, they must at least fulfil WHO's criteria for screening to get priority. When a decision is made, the case should be designated as the basis for use in similar cases in the future. In this manner one establishes what Daniels and Sabin called case law, and ensures that similar cases are treated alike.

In 2010, it was carried out an evaluation of the Council (Evaluering 2010). The report states that although the Secretariat is small, it has many large tasks. The evaluation determined that it is necessary to apply additional resources for the Council to achieve its full potential. This is in accordance to this thesis. Due to the secretary's many tasks, the objective of a transparent decision-making is not fully reached. However, this evaluation gives the Council the opportunity to become more aware of what they post of relevant information. The key is clarity. Clarity in this context is achieved not only by being linguistic aware, but also aware of what information they actually make public available.

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